Sociological Study of Disease and Healthcare: A Case Study of Hemoglobinopathies in Balasore District of Odisha

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(A Synopsis for Ph.D. Degree in Sociology)

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Introduction

The study deals with the social aspects of hemoglobinopathies. It will be based on both quantitative and qualitative data in a descriptive research design taking Balasore District as a case study. Initially purposive sampling then simple random sampling strategies will be used for the study. The three hundred respondents will be selected for the collection of primary data through interview schedule and observation from District Headquarter Hospital, Balasore and other regions of the district. Secondary data will be collected from the different published materials as per the requirement of the study. The aim and objective of the study is to know the socio-economic background, to study the sociological variables like caste, class, gender and so on associated with the diseases and to analyse the problems and issues of indexed hemoglobinopathies patients in Balasore District of Odisha.

Statement of the Problem

Hemoglobinopathies are the most common hereditary blood disorders and one of the world's major health problems. With approximately 7% of the worldwide population carriers an abnormal hemoglobin gene, they were originally found mainly in the Mediterranean area and large parts of Asia and Africa. International migration has spread them from those areas all over the world (WHO, 2006). Annually 3,00,000 to 5,00,000 children are born with clinically significant haemoglobin disorders. Majority are affected with Thalassemia and Sickle Cell Disease (WHO_TIF Meeting, 2007). Only next to infectious disease, hemoglobiopathies represent a major health issue in India. Thalassemia and Sickle Cell Disease are also reported to be quite common among the population of Odisha state (Kar et al. 1987).

Despite the scientific evidence, improvement of medical science many social superstitions, stigma, traditional thought, cultural barriers are rooted in the society. Still people believe that diseases are God gifted we have no control over it. These misconceptions affect the quality of care individuals with hemoglobinopathy disorder and the amount of money devoted to hemoglobinopathy research and advocacy. Put in more sociological terms, the way we socially construct hemoglobinopathy disorders influences the social structures that surround it. Here is the study of concern that how social aspects influence this hereditary blood disorder and vice versa. In other word, social variables like caste, class, gender, ethnicity, race, pattern of marriage, education, etc and its impact on hemoglobiopathies.

Sociological Theories

The link between medical sociology and sociological theory is crucial to the sub-discipline. There have been three dominant theoretical perspectives in the history of medical sociology or sociology of health and illness. These are functionalism, conflict perspective and symbolic interactionism which are discuss below for the present study.

Functionalism

According to the functionalist perspective, health is vital to the stability of the society, and therefore sickness is a sanctioned form of deviance. Talcott Parsons (1951) was the first to discuss this in terms of the sick role: patterns of expectations that define appropriate behaviour for the sick and for those who take care of them.

Thus hemoglobinopathy patients are not the functional members of the society. They have their own rights and obligations for improvement of health condition and better lifestyle.

Conflict Perspective

Theorists using the conflict perspective suggest that issues with the healthcare system, as with most other social problems, are rooted in capitalist society. According to conflict theorists, capitalism and the pursuit of profit lead to the commodification of health. In this view, people with money and power the dominant group are the ones who make decisions about how the healthcare system will be run. They therefore ensure that they will have healthcare coverage, while simultaneously ensuring that subordinate groups stay subordinate through lack of access. This creates significant healthcare and health disparities between the dominant and subordinate groups.

Here the hemoglobinopathy disorders and its health care system and management in Odisha is concern, the costs of medicines, food charges, travelling expenses and the loss of daily income put a heavy economic burden on these families. Heavy economic burden and social isolation causes psychological problem in these patients and their parents in such that sometimes they think of committing suicide. These parents think that affected child is a curse for the family.

Symbolic Interactionism

According to theorists working in this perspective, health and illness are both socially constructed. Interactionists focus on the specific meanings and causes people attribute to illness. The major figures in early medical sociology working in the symbolic interactionist

tradition were Anselm Strauss and Erving Goffman. In his theory of "social stigma", Goffman explain than an ill person or stigmatized person spoils their normal identity. They pose socially abnormal behaviour which is not accepted by the society (Goffman, 1963).

As such, this study endeavoured to ascertain how these hereditary blood disorders manifested in social interactions within the society. Patient's perceptions of the disease will be based on what it means to them. Meanings are defined through interactions with others, which will ultimately decide whether a disease is perceived as a negative condition and consequentially disclosed or not. Meanings of the disease can change over time as a result of experience, circumstances and interpretation.

Postmodern Perspective

Postmodernist perspectives in the sociology of health and science challenge traditional, grand-narrative approaches to understanding health, illness, and medicine. Emphasize the role of cultural, social, and political forces in shaping knowledge, practices, and understandings related to health and scientific inquiry. They also advocates for medical pluralism, recognizing that multiple forms of knowledge (scientific, traditional, indigenous) coexist and should be valued equally. It also adopts relativism, arguing that "truths" in science and health are contingent and context-dependent rather than absolute.

Michel Foucault the postmodern critiques of sociology of health and science. He explains his theory on power and knowledge that, the health systems, medical practices, and scientific research are seen as mechanisms of power that regulate and control populations by defining what is "normal" or "healthy". Scientific discourses are tools for legitimizing power and marginalizing alternative perspectives, such as traditional or indigenous healing practices (Foucault, 1976).

Another post modern thinker Bruno Latour in his actor-network theory, challenges the notion that science operates independently of social and material influences. He advocates that science and health as the outcomes of networks of human and non-human actors (e.g., researchers, institutions, technologies, funding bodies). Scientific "facts" are not discovered but constructed through these networks. Example: A vaccine's development involves scientists, pharmaceutical companies, government regulators, funding agencies, and the public (Latour, 1887).

Here adopting the postmodernist perspective, sociological analysis to uncover the complex, contested, and socially constructed nature of hemoglobinopathies in Balasore. It emphasizes that how the interplay of power, knowledge, culture, and local context in shaping the experience of disease and healthcare, offering a distinct and pluralistic understanding of the issue.

Review of Literature

Consanguineous marriage appears to contribute significantly to the frequency of affected births in turkey. Out of the 14 homozygous foetuses with hemoglobinopathies, six were the result of close consanguinity **(Tuzmen et al. 1996).**

Clementic et al. (2003) were conducted a study to explore the rate of psycho-social dysfunction in affected and non affected children with haemophilia or beta thalassemia. Children with beta thalassemia showed significantly higher rates of social dysfunction then their unaffected siblings. Older children showed significantly higher social dysfunction at school.

Xandra et al. (2008) studied the quality of life of care givers in Netherland. Care givers of patients with sickle cell disease had a significantly lower quality of life.

A study was undertaken to assess the cost of caring children with beta thalassemia in Thailand. The annual average cost of treatment was 59% direct medical costs, 17% direct non-medical costs and 24% indirect costs **(Riewpaidoon et al. 2010).**

A study was done by **Ismail et al. (2018)** to evaluate the health-related quality of life (HRQoL), muscular strength and pain in children with bet thalassemia major in Egypt. The study shows that the beta thalassemia has a negative impact on muscular strength, pain and HRQoL in terms of physical, psychological, social and school functioning of the children.

Research Questions

After review the exiting literature so many questions arises, few selected research questions will be undertaken for the present study.

1. What is the socio-economic status of hemoglobinopathy patients of Balasore District?
2. How the sociological variables associated with hemoglobinopathies?
3. What are the major health and other related problem and issues faced by them?
4. How effective are government policies and programmes in control and prevention of hemoglobinopathies?

Research Objectives

In order to achieve the aim of the study, the following objectives will be undertaken for the present study.

1. To know the socio-economic background of the hemoglobinopathy patients.
2. To study the sociological variables associated with hemoglobinopathies.
3. To analyse the problems and issues of the hemoglobinopathy patients.
4. To assess the government policies and programmes for hemoglobinopathies.

Research Design and Methodology

The research will be based on both quantitative and qualitative in a descriptive research design. The data will be collected from both primary and secondary sources. But keeping the level of accuracy in mind, maximum will be dependence on primary data and secondary data will be used as per the requirement of the study.

Sources of Data

Primary data will be collected from the selected field through observation and interview schedule methods by the researcher himself, whereas the secondary data will be collected from different published materials like books, journals, magazines, newspapers, archives, government and non-government reports, etc. The hemoglobinopathy cases will be reporting from District Headquarter Hospital, Balasore, and different regions of the district.

Sampling

The selection of participants will be those, who have affected with hereditary blood disorders. So purposive sampling strategy will be use for the purpose of participants recruitment to help achieve data for the study. Three hundred respondents will be taken as a sample size of 20% (probably) of total hemolgobinopathy cases of the district.

Social Parameters

The following social parameters pertaining to **Socio-economic aspects:** age, gender, education, occupation, income, etc. **Social construction of the disease:** sub-caste/tribes, marriage pattern of the parents, affected siblings, knowledge and awareness about the disease etc. **Problems and issues:** physical health, economic problems, psychological dimensions, socio-cultural issues of patients, etc. **Government policies & programs:** different policies & programs under National Health Mission and so on will be included in the present study.

Analysis of Data

The standard statistical tools like correlation, chi-square statistics, statistical figures, cross tabulations, percentage will be used to classification, tabulation and analyse the data generated from the various investigation of the present study. Statistical Package for Social Science (SPSS) and different Artificial Intelligence (AI) tools will be used for statistical analysis and presenting the data in different forms.

Significance of the Study

The review of the existing literature suggests that the social construction of hemoglobinopathies likely to be influenced by a wide range of sociological variables and contextual factors. Like other chronic disorders, patients with hemoglobiopathy disorders are suffering physically, clinically, mentally and financially as these diseases are genetic in nature and there is no permanent cure for such diseases.

Based on the referred hospital samples about the prevalence of hemoglobinopathies in Odisha, it is shows that the spectrum of hemoglobinopathies is so high in northern part of Odisha. Among the northern part of Odisha, mainly in Balasore has the highest frequency of hemoglobinopathy cases (Mishra, 2011 and Das, 2018). This is the main purpose, motivation, and reason in selecting the Balasore District of Odisha as the universe of the present study.

A lot of studies have been conducted in Odisha, with only a few in Balasore, specifically regarding the occurrence of hemoglobinopathy disorders and their biological, clinical and haematological impact on the human body. But the social, cultural studies yet not much more conducted. It is highly necessary to study these aspects so as to plan and execute the future management, prevention and control strategy for such disorders in the society.

Future Work

The Balasore District is inhabited by 23,20,529 people comprising of 11.9% Schedule Tribes (ST) and 20.6% Schedule Caste (SC) (census 2011). There was no such caste wise data of hemoglobinopathies cases in Balasore. Based on the referred hospital samples it was known that the hemoglobinopathies cases are very common among the general castes groups in Balasore. For the prevention of this disease it is highly essential to have the base line data on hemoglobinopathies. The pattern of hemoglobinopathies mutation and their regional as well as caste wise frequency has to establish. There need to be comparative studies on social aspects between hereditary disorders and infectious diseases. Further a study on the social aspect of hereditary blood disorders should be taking whole Odisha as a case study.

Tentative Chapterization

The entire research work will be divided into seven chapters.

Chapter-I: will be introduction and conceptual framework.

Chapter-II: reports the existing literature on the social aspects of hemoglobinopathies.

Chapter-III: contains with socio-economic background of hemoglobinopathy patients.

Chapter-IV: examines the social construction of hemoglobinopathies.

Chapter-V: focuses on the problems and issues of hemoglobinopathy patients.

Chapter-VI: assess the government policies and programs on hemoglobinopathies.

Chapter-VII: provides summary and conclusion, followed by bibliography and appendixes.

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